

Outcome/ Data Analysis Subcommittee Meeting
2/1/07 10:00 AM to 1:00 PM

ITEM	DISCUSSION	ACTION
Purpose of the Subcommittee	Develop quantitative evaluations, qualitative surveys, and quality care indicators that will be used to evaluate the impact of the Pediatric Palliative Care (PPC) Pilot Projects	
Chester Randle, M.D., Chief, Program Development Section Introductions	Committee Members who were present (in person or on phone) introduced themselves and their programs: Ann Pomper: Hospice of Santa Cruz Christy Beaudin: Chief Quality Officer-CHLA Devon Dabbs: Children's Hospice & Palliative Care Coalition Lori Butterworth: Children's Hospice & Palliative Care Coalition John Golenski: George Mark Children's House Jenny Mann Francis: U.C. Davis Medical Center Joan Tanzer: George Mark Children's House Joyce Shefren: Pathways Home Health, Hospice & Private Duty Margaret Clausen: California Hospice Organization Marian Dalsey, M.P.H., M.D., Chief, CMS Branch Pam Christiansen: Nurse Consultant, CMS Branch Jan Burrow: Nurse Consultant, CMS Branch Galynn Plummer-Thomas: Nurse Consultant, CMS Branch Xavier Castorenas: Social Work Consultant, CMS Branch Carmen Romo: Research Analyst, DHS, MCP-RDB Kathy Bissell-Benabides: Health Program Specialist, MCP-RDB	
Review of Pertinent References	Assembly Bill 1745 Materials from Children's Medical Services Branch Death Certificates for 2004, Age <21 yrs by County of Residence Death Certificates for 2004, Age <21 yrs by County of Death California Children's Services Clients by Diagnostic Code	No Action

	<p>Handout of CCS eligible conditions from CCS website.</p> <p>Specific articles of interest Hayes, et al The Seattle Pediatric Palliative Care Project: Effects on family satisfaction and health-related quality of life. J Palliative Medicine 2006;3:716-728 Himmelstein, et al. Medical Progress: Pediatric Palliative Care. New Engl Journal of Medicine 2004;350:1752-1762 Feundtner, et al. Deaths attributed to pediatric complex chronic condition: National trends and implications for supportive care services. Pediatrics 2001;107(6)</p> <p>Eligibility decision was made 1/31/07, to use the New England Journal of Medicine groupings of condition categories + Washington State's eligibility criteria</p> <p>Florida Waiver has references to Tools used Quality of Life Pain and Symptoms Family Stressors</p> <p>Office of Statewide Health Planning & Development (OSHDP) Annual Report to determine number of children getting the hospice benefit</p> <p>Rand compared adults hospices vs. non-hospices: conclusion non-cancer adults needed more services = higher cost of care</p> <p>Calif. health Info Survey-UCLA/DHS sponsored- 2 year random phone study</p> <p>2003 Atlas Study: Acute Care-Medicare-Cost of Intensive Care Services vs. Hospice services in decedents (reviews the cost of care the last months of life)</p>	
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	<p>National Hospice & Palliative Care Organization (NHPCO) Family Satisfaction Survey completed 3-6 months post death</p> <p>Stanford to do focus groups with parents of children undergoing treatment</p> <p>Agency for Health Research & Quality (AHRQ) Washington DC for cumulative data</p> <p>NHPCO has a family satisfaction survey (they are working on developing a survey for parents)</p>	<p>Devon Dabbs to find out when this survey will be ready for use</p>
Processes (or costs) to capture and measure	<p>Specific methodologies/validity</p> <p>Partnership for Parents (PartnershipforParents.org) has a parent satisfaction survey – the group surveyed is self selected and may not serve as a good control group to use to compare satisfaction of parents in the Pediatric Palliative Care Waiver project.</p> <p>Special Care Centers have their own (probably unique) Satisfaction Surveys</p> <p>The Federal CMS will require an independent evaluation of the pilot projects.</p> <p>Federal Waiver Reporting Requirements Number of persons served Diagnoses of persons including ICD-9 codes Paid Claims for waiver services</p>	<p>Marian Dalsey, M.D. to identify an independent agency that will do an external evaluation preferably using an interagency agreement.</p> <p>Carmen Romo to get information on how services and costs are measured</p>

	<p>Information needed to determine Effectiveness of the Waiver</p> <p>Quality of Life Scale (probably PedsQL)</p> <p>Pain and Symptom Scales</p> <p>School Attendance (see Florida Waiver)</p> <p>Consider Stein & Jessup 1985 Impact on Family Scale</p> <p>Family Functioning assessment (Margaret Clausen knows of one)</p> <p>Economic Impact on Family (see Florida Waiver and Hayes study)</p> <p>Provider Satisfaction Survey (see Florida Waiver)</p> <p style="padding-left: 40px;">to assess Hospices, Special Care Centers, local CCS offices, and Care Coordinators</p> <p>The pilot needs to assessments that can be translated into 12 threshold languages.</p> <p>Identify methods to access the impact of enhanced therapies such as Child Life and Art Therapy</p> <p>The goal should be to use the same scales that other states are using to improve consistency of evaluations.</p> <p>Determine Enrollment Effectiveness</p> <p>The waiver will require the following:</p> <ul style="list-style-type: none"> # of CCS Clients potentially eligible for the Waiver # of CCS Clients offered enrollment into the pilot project # of CCS Clients who were offered enrollment and accepted <p>We need to determine the number of clients that need to be in the program to show statistically significant differences in outcomes in the pilot project families and standard care families. Need to get input from epidemiologist.</p>	<p>Jan Burrow to Contact Sutter Hospice for information about assessment tools.</p> <p>Dr. Randle to identify state resources for epidemiologist.</p>
Next Meeting	March 15, 2007 10:00 AM – 1:00 PM	Before the next meeting, Dr. Randle to compile the assessment tools based on subcommittee recommendations.

